DOCUMENT RESUME

ED 334 749 EC 300 495

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TITLE Family Support Services and Residential Options for the Mentally Retarded in the U.S.: New Service Paradigms and Models.
INSTITUTION Community Research Associates, Pittsburgh, PA.; Health and Welfare PLANNING Association, Pittsburgh, PA.
SPONS AGENCY Edith L. Trees Charitable Trust.
PUB DATE Nov 90
NOTE 57p.; For a related document, see EC 300 494.
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Adoption; Adults; Community Programs; *Delivery Systems; Demonstration Programs; Housing Needs; *Housing Opportunities; Independent Living; Innovation; *Mental Retardation; *Models; Normalization (Handicapped); Older Adults; Social Integration
IDENTIFIERS Pennsylvania

ABSTRACT

This report outlines emerging paradigms of service for mentally retarded adults emerging from a nationwide search for innovative programs and practices. It was prompted by the consistent finding of a Pennsylvania longitudinal study that mentally retarded school completers tend to live indefinitely with parents or guardians. The study found the most common family support services in the nation are respite and child care, environmental adaptation, and family counseling. Noted among Pennsylvania's services is the Family-Driven Family Support Services Program in which persons with mental retardation and their families decide which services will best address their needs. Four programs that create innovative housing options for the mentally retarded are featured. The following three programs develop permanent housing arrangements in the community: Family Consortiums in Ohio (parents or guardians form a consortium which manages a certified home); the Resource Center for the Elderly in Illinois (matches adults with developmental disabilities with community residents in mutually beneficial shared living arrangements); and Prairie Housing Cooperative in Winnipeg, Manitoba, Canada (clusters of housing in which one unit is occupied by a handicapped individual). Project S.T.A.R. (Specialized Training for Adoption Readiness) in western Pennsylvania is an adoption agency for children with disabilities. Includes 45 references. (DB)

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FAMILY SUPPORT SERVICES AND RESIDENTIAL OPTIONS FOR THE MENTALLY RETARDED IN THE U.S.:

NEW SERVICE PARADIGMS AND MODELS

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November, 1990

EC 300495

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This research was funded by a grant from the Edith L. Trees Charitable Trust. The views in this paper are not necessarily those of the Trees Trust.

FAMILY SUPPORT SERVICES AND RESIDENTIAL OPTIONS FOR THE MENTALLY RETARDED IN THE U.S.: NEW SERVICE PARADIGMS AND MODELS

EXECUTIVE SUMMARY

This year's focus on support services and residential options for the mentally retarded is a new element of the CRA/HWPA research projects supported by the Edith L. Trees Charitable Trust. It was prompted by the consistent finding of our ongoing follow-up study that local mentally retarded school completers tend to live indefinitely with parents or guardians. We set out to determine what was available in support services and residential options for the mentally retarded across the country, focusing on innovative models. We mounted a nationwide search for programs and practices, especially seeking those that served the severely impaired.

We learned that there are, indeed, innovative and exciting programs in evidence. Many specifically include the most severely retarded. We also found that there is a shift in what is being defined as best practice in support and residential services. The system is moving beyond the traditional continuum of residential services arrayed from "most restrictive" to "least restrictive". It is moving toward more individualized, integrated and community-based services.

This report outlines emerging paradigms of service as defined by those on the forefront of program planning. It describes new service models that embrace these ideals and have been implemented at various sites. Some of these principles and programs are described below.

Support Services in the U.S.

Support services are a critical element in the growth of new approaches to residential services. They enhance families' abilities to care for children, preventing them from being placed out of their homes. They enable new residential models to be developed, especially when they are not linked to specific residential alternatives, but can follow individuals wherever they live.

The most common family support services in the U.S. are respite and child care, environmental adaptation andfamily counseling. There is tremendous variability in the level of support services available around the country. Some states and counties place little emphasis on comprehensive support services, and few services are available in these locations.

Services and Programs in Pennsylvania

Pennsylvania makes provision for a wide array of family support services, including respite, homemakers, recreation and

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financial assistance. Extent and quality of service varies from county to county. The state has mounted a new initiative, Family-Driven Family Support Services, in which persons with MR and their families decide which services will best address their needs. This program is currently being tested in pilot projects. Pennsylvania's Family Living Program is a community residential services option in which 1-2 individuals with MR live in the home of an unrelated adult or companion. In 1990, approximately 250 adults and children were served in family living homes.

Innovative Residential Models from Around the Country

The Center on Human Policy, University of Syracuse, conducted a national search for model programs which strive to integrate people with severe and profound mental retardation into their natural communities. The site reports from the Center are the type of material the present author envisioned for this research - detailed descriptions of innovative programs from around the country. A number of programs described in these reports are presented: 1) Options in Community Living and Columbia County, Wisconsin, which support people with disabilities living in the community; 2) Professional foster homes and supervised apartments, Washington County, Vt.; 3) The No Name Program, Burlington, Vt. in which three very disabled people live with a family; and 4) Family Supports in Montana, a rural program which strives to prevent children fom being placed out of families, and to return them to the community from more restrictive environments.

Four additional programs which create innovative housing options for the mentally retarded are featured. The first three develop permanent housing arrangements in the community, to which supports are then provided. The fourth arranges adoptions of disabled children.

Family Consortiums, Ohio

* Parents or guardians of developmentally disabled adults or children form a consortium which manages a certified home in which the disabled individuals reside.

* Staff are selected by the consortium, which is solely responsible for their hiring, firing and evaluation.

* The program costs the state less money than group homes. Each individual living in a consortium-run home costs the state $25/day, rather than $75/day.

Shared Housing for Special Populations Project: The Resource Center for the Elderly, Ill.

* This program matches adults with developmental disabilities with community residents to live in mutually beneficial shared living arrangements.

* In exchange for living space, support is provided for the homeowner in the areas of finances, and/or assistance with housework, errands or companionship.

* 3 matches have been made since January, 1990, with more imminent. There have been 6 matches since the program started two years ago.

Prairie Housing Cooperative - Winnipeg, Canada

* The co-op purchases "clusters" of 2 to 4 neighboring houses or apartment units. One unit in each cluster is occupied by someone who needs extra assistance.

* No more than 2 handicapped people live in a household. Families and individuals without handicaps are recruited to live nearby or to share a house with a person who has a handicap.

* Organizers rely heavily on informal and natural supports between members. Relationships are voluntary, and housemates share equally in household expenses.

* By the of fall 1986, the program involved 60 people in 20 households; 12 of these had mental handicaps.

Project S.T.A.R. (Specialized Training for Adoption Readiness) Permanency Planning Advocates of Western Pennsylvania

* S.T.A.R. is an adoption agency for children with disabilities, the only such agency in the U.S.. It is located in Pittsburgh, PA.

* It has placed 55 children since its founding in 1985. Approximately 98% have an MR involvement, some profound. Referrals tend to be children in institutional settings and foster homes.

* S.T.A.R. has placed children from birth to 18 years old; the majority are 2-8 years old.

Concluding Remarks

This report presents principles that underlie new approaches to residential and support services for the mentally retarded across the country, and innovative service models based on these. These new principles and practices may herald a fundamental difference in the way service systems for the mentally retarded come to be structured - systems based on services and not facilities, that enable individuals to remain in the community, in homes and families of their choice. Whether, how quickly, and how successfully these new paradigms will come to characterize support and residential services to the *majority* of mentally retarded individuals across the country remain to be seen.

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INTRODUCTION

This year's focus on support services and residential options for the mentally retarded in the U.S. is a new element of the CRA/HWPA research projects supported by the Edith L. Trees Charitable Trust. It was prompted by the findings of the follow-up study of mentally retarded school completers that we have been carrying out since 1987. Our consistent finding has been that the great majority of youngsters continue to live with their parents after leaving school. This characterized over 80% of most of the groups of mentally retarded youngsters followed each year. This year's survey, which followed youngsters who have been out of school for four and five years, found over 70% of these youngsters, now generally 24 to 26 years old, to be living at home with parents (Gordon and Goldbach, 1990).

We explored this situation further in last year's interviews with parents (Gordon and Goldbach, 1989). We found that most parents whose youngsters were living with them were quite satisfied with this arrangement, had not explored the possibility of their son or daughter's living away from home and expected him or her to still be living with them in five years. When asked about their plans for the future, parents would typically say that their youngster would live with them "forever". 50% of parents indicated that their own infirmity or death were circumstances that would lead them to consider their youngster's living away from home. They most frequently cited "living with a sibling" as the youngster's likely residential arrangement should these events transpire.

These findings elicited some uneasiness on the part of the researchers, in light of questions about whether the prevailing situation as to living arrangement was optimum in terms of: 1) the youngster's development and autonomy, 2) the probable necessity for a change in residence when the mentally retarded individual would likely be middle-aged and have considerable difficulty adjusting, 3) the implications for the lives of the caretaking parents, now and in the future, and 4) the potential impact on siblings' lives.[1]

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[1] As these words were being written, an article appeared detailing the situation of parents living with retarded adult offspring which echoed these concerns. The predicament of these parents in their 70's and 80's, who had always cared for their sons and daughters, now in their 30's and 40's, was reported. The parents were depicted as agonizing over their adult children's futures, desparately trying to find acceptable living situations for them while not burdening their other children: "I don't want to leave the problem for my other children . . . . I worry about getting Johnny settled somewhere before something happens to me". (Lewin, 10/28/90).

This prompted a feeling that "there must be something else out there"; some residential options developed somewhere that both mentally retarded individuals and their parents are comfortable with, and even enthusiastic about. There must be living arrangements that are good for youngsters - fostering their growth and meeting their need for companionship with peers - while also fulfilling their parents' requirements for safe, secure, neighborhood-based housing. We became convinced that there must be more out there in terms of residential arrangements for the mentally retarded than those in which we found our youngsters living.

We decided we wanted a chance to broaden our horizons; to expand the way we were seeing these services and to see what the potential was for living arrangements for mentally retarded youngsters. We proposed to mount a nationwide search for programs and practices that were more than we were seeing within the geographic confines of our previous investigation.

We felt that the search for residential options was especially critical in terms of more severely retarded youngsters. Those that we had been following in our studies were found primarily in two situations: living with their parents or in institutions[2]. These seemed to us to be very traditional choices, ones that had been around for a long time. Was this an area in which new options could also be evidenced? Our search, therefore, included the proviso that we were especially interested in innovative residential models for the *severely impaired*.

Along with new residential alternatives, we also wanted to determine support services available around the country. Our study findings, corroborated by a series of local newspaper articles (Blazina, 1989a,b,c,d,e), indicated the difficulties encountered by parents caring for mentally retarded offspring at home, especially those more severely retarded. Such parents tend to feel that the service system has failed to meet their needs for services such as in-home help, respite care and recreation programs for their youngsters. Extreme care demands coupled with a paucity of resources often appear to make these families' lives extremely trying. We were aware that new Federal Medicaid waivers to states offered opportunities for the creation and expansion of systems for support services and were therefore interested in learning what new developments were in evidence. We wanted to discover the status quo in the country in terms of family support services and saw this as a major goal of the data

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[2] It also should be noted that the only changes that we have seen in the living arrangements of the severely/profoundly retarded in the four years of follow-up occurred this year, when three individuals *moved into institutions*. (Gordon and Goldbach, 1990)

collection effort.

Our project then, became one of determining the state of the art in the U.S. in respect to family support services and residential options for the mentally retarded, especially the severely impaired. We set out to answer such questions as:

- What support services are available to families?
- Which are most common?
- How extensive is the range of support services available to a family?
- What are the different ways that support services are provided to families? What are the pros and cons of each approach?
- Can we identify innovative models of residential arrangements that offer more to their clients then those typically seen? Do they serve severely handicapped individuals?
- What are the characteristics of such models? What are their underlying principles?
- What are the trends in residential services? In what direction do they appear to be moving?

Methodology

We set out, then, with the goal of finding out what was available in support services and residential options for the mentally retarded across the country. We focused on innovative models - models that incorporated new ideas and might serve to spark ideas for program development. We were especially interested in those that had potential for more severely impaired individuals.

We really didn't know what was out there, and so embarked on this information-gathering adventure with the advantages and disadvantages of the naive observer, with few preconceptions of what would be found. The search for information took a number of directions. As the search was for *innovative* models, we were aware that, in the nature of things, many of these would not be published, but would be available only in project brochures, unpublished program descriptions and progress reports. The effort to locate pertinent material began with a literature search which involved reviewing relevant journals, and scanning bibliographies such as the ERIC system. An important aspect involved contacting potential information sources. We drafted a letter describing the project and our aims, asking for "any

possible information relating to new approaches to in-home and residential services for the severely retarded and their families". This was, first of all, sent to the State Offices of Mental Retardation in all 50 states. We sought other potential sources, writing to foundations that focused on the mentally retarded, and university centers and institutes known to be involved in this field. We also kept our eyes open for references to possible projects and followed up on these by writing to key personnel. As happens with such efforts, the responses to the initial letters suggested additional possibilities, or mentioned reports that might be of interest, and we followed up on these. The result was hundreds of letters sent, and a plethora of material collected.

The next stage of the project, (concurrent with the first, as data gathering continued throughout), involved reading, sorting, organizing and analyzing this great bulk of material. The goal was to derive a sense of communalities across the programs - the principles that underlay the new approaches - and to select models that would best serve to illustrate these.

Findings

Our search yielded more than we had bargained for. Rather than simply discovering relevant programs, we learned that there is a whole new world out there. There are indeed, innovative and exciting programs in evidence. Beyond that, however, there appears to be a profound shift in the way that planners on the cutting edge are viewing these service systems. We seem to be undergoing one of those periods of paradigm shift that reoccur in the social services. A change is underway in what is defined as best practice in support and residential services. On the cutting edge, development of support services and residential models tends to be guided by new principles; new ways of envisioning possibilities for the mentally retarded.

These new ways also, and quite emphatically, include the most severely retarded. Many of the new models are specifically designed to include provision for these individuals. As will be illustrated in this report, there are examples of severely impaired people living in community-based accommodations, receiving the support services that permit them to reside in such arrangements. Options for these individuals have been substantially expanded by the new approaches.

Keeping One's Perspective

A particular problem emerged in discussing the new approaches. It became clear in reading the collected material

that one can get carried away by these initiatives - the excitement of innovations being tried and new opportunities being opened up - and lose sight of the fact that *these are not the status quo; these principles and approaches do not characterize services to the MR in this country.* The methodology of this paper makes it impossible to determine the numbers affected by the new approaches as compared with those whose lives are shaped by traditional services. It does appear that the vast majority of people served are *not* in such innovative options, but rather are being served by traditional services and programs.[3] It is also clear that there are areas of the country where *none* of the new approaches are happening, that are largely untouched by the emerging paradigm shift.

One of the dilemmas of this paper, therefore, became how to present what is becoming accepted as optimal planning principles and models embraced by agencies on the cutting edge, while at the same time not losing sight of the fact that *these do not characterize the major body of services in this country.* The danger in not keeping this firmly in mind is that advocates of such approaches will assume that they have been widely established, rather than that they have been *established in particular, limited circles.* Such an assumption would tend to obscure how far the country actually is from embracing this view, and how much work would need to be done for it to become the norm. The reader, consequently, is asked to share with the author the task of keeping the new principles and services in perspective within the larger domain of traditional services which continue to characterize the field at present.

The Content of the Report

This paper, then, presents what appears to be emerging as accepted paradigms of service by those on the forefront of program planning for the mentally retarded. It also describes new service models that embrace these ideals and have been implemented at various sites. In so doing, it may, perhaps, be indicating the direction in which the field is evolving.

Being based on secondary sources, the report has some of the features of a literature review. At times, particular references

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[3] There is, for example, current talk of "less emphasis" on large institutions and group homes with over 4 people. But a recent article in the New York Times jolts us back to a different reality. It reports that 84% of Federal Medicaid money for the mentally retarded in 1988 went to institutions of 16 or more, and only .07% to home and community-based services, indicating that the former received 1200 times the resources of the latter (Holmes, 10/14/90).

form the basis of certain sections. This reliance on specific sources will be indicated where it occurs.

Two resources should be mentioned as having been especially salient to this research. The first is the Center on Human Policy, Research and Training Center on Community Integration, Syracuse University, which we found by tracing back the source of a number of ERIC documents that appeared to be exactly what we were seeking. This Center has been looking into the "state of the art" in community integration for people with disabilities for a number of years. Its publications, including model program site visit reports, were invaluable. On the support services side, we discovered an extremely useful up-to-date publication that summarized what was going on in the country: Knoll, James A. et al, Family Support Services in the United States: An End of Decade Status Report, Cambridge, MA.: Human Services Research Institute, 1990.

Responsibility for the overall organization, analysis, and conclusions of the paper lies, of course, completely with its author.

The report begins with a discussion of the way in which residential services have been conceptualized since the 1970's, the continuum concept, which is currently being challenged by the new approaches.

CONTINUUM CONCEPT[4]

The concept of a continuum of services has been guiding residential service systems for the mentally retarded for more than a decade and is the way most such systems are currently designed. The continuum can be conceptualized as a straight line running from "most restrictive" to "least restrictive" placement (see next page). The most restrictive placements involve segregated facilities such as residential institutions; the least restrictive placements involve normal settings such as independent living.

The continuum concept was developed in the 1960's to refer to a range of special education placements from the hospital to the regular class. Years later, the federal regulations for special education services incorporated this concept in P.L. 94-142 and required a "continuum of educational placements". The continuum concept caught hold in regard to residential services in the 1970's. It represented an appealing alternative to the limited choice of institutionalization or community living with no supports. Most states incorporated the continuum concept in their design of residential services, a structure which remains in place in most states. For example, the regulations currently guiding Pennsylvania's residential services for the mentally retarded state:

> The system of residential services is designed to assure opportunities for mentally retarded persons to progress along a continuum of services generally characterized by movement from larger to smaller settings, group to individual residences, dependent to independent living, and movement from isolated settings to integrated living within the community. (Regulations for Community MR Facilities. Chapter 6400.1. Introduction, August, 1986)

There are a number of assumptions inherent in regarding residential services as located along a continuum. The first is that people with the most severe disabilities will be served at the continuum's most restrictive end and those with the mildest disabilities at the least restrictive end. The second is that as people acquire additional skills they are expected to move from more to less restrictive settings. For example, a person might start out in an intermediate care facility, receive training and

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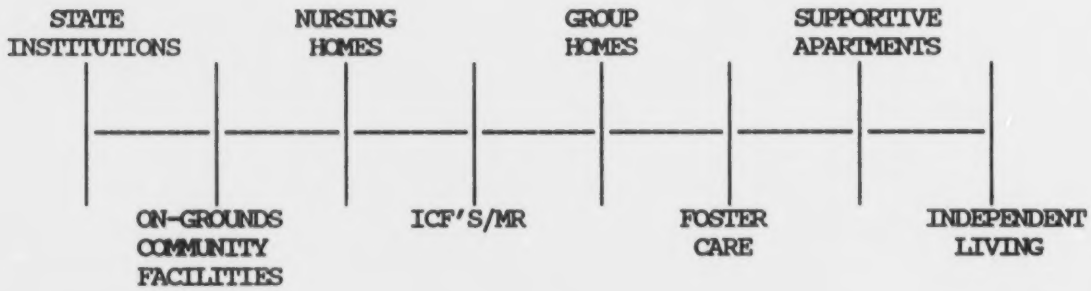
[4] The sections of the report describing the continuum concept and the criticisms of this concept are based on the discussion in: Taylor, Steven J., Racino, J.A., Knoll, J.A. and Lutfiyya, Zana, The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities, Syracuse: Human Policy Press, 1987, pp. 7 - 11.

then move to a group home. After several years in a group home, he or she might be allowed to "try" a supervised apartment. If successful, the individual might then make the move to a semi-supervised setting and then, at last, be transferred to an unsupervised apartment.

THE CONTINUUM OF RESIDENTIAL SERVICES[5]



As seen above, the residential continuum generally consists of the following types of placements:

1) **Institutions** - These are large public institutions which have traditionally housed hundreds of people. This is where some people think those with severe disabilities belong. The populations of public institutions for the mentally retarded and developmentally disabled have declined at a steady pace since the late 60's to approximately 111,000 in 1985. They now include a growing percentage of individuals with severe and profound retardation, multiple disabilities and behavioral involvements.

2) **On-grounds "community facilities"** - These are newly constructed units on the grounds of public institutions. Several states are currently involved in constructing clusters of 8-12 bed "group homes" at old institutions.

3) **Nursing homes** - In the early and mid-70's especially, many people were "deinstitutionalized" from large public institutions to nursing homes. Lakin et al (1982, cited in Taylor et al, 1987) estimate that in 1980 over 69,000 individuals with mental retardation were living in nursing homes.

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[5] This figure, with slight modification, is from: Taylor et al, 1987, op. cit.

4) **Community Intermediate Care Facilities for the Mentally Retarded (ICF's/MR)** - These are Medicaid-funded facilities which range from smaller group homes to institutions for hundreds of people. Some states have placed a large number of people with severe disabilities in ICF's/MR.

5) **Group homes, community residences, halfway houses** - When most people think of community living for the handicapped, they tend to think of group homes which generally house from 6 to 12 individuals. Few people with severe disabilities have been served in group homes.

6) **Foster homes, "family care", "specialized foster care"** - One of the first alternatives to institutionalization for people with developmental disabilities. In traditional foster care, families receive a room and board payment for persons in their home. More recent "personal care" and "community training homes" programs provide payment to foster families for training those individuals placed in the home. In most states, foster care has been used for adults and children with mild disabilities. In Nebraska and Michigan, people with more severe disabilities have been involved.

7) **Supportive apartments, semi-independent living** - This term usually refers to "transitional" apartments for people with mild disabilities. People in these programs receive supervision and support on an "as needed" basis.

8) **Independent living** - Independent living for the mentally retarded can mean everything from living with the support of friends and families in decent housing, to living in substandard conditions totally outside human service systems. Some street people, early victims of well-intentioned deinstitutionalization efforts, fall into this category.

The continuum concept was considered to be very advanced when it was developed. With time, however, practical experience has indicated a number of problems with visualizing the system of residential services in this way. Critics of the continuum concept have pointed out the following:

Criticisms of the Continuum Concept

1) **The severely disabled get stuck at most restrictive end.** Movement through the continuum does not tend to occur for severely disabled individuals.

2) **More restrictive placements do not prepare for less**

restrictive. The skills needed to live in the community - functioning in a home, a restaurant, a store - do not tend to be learned by living in a segregated setting.

3) **The "most restrictive" placements aren't necessary.** People with severe and profound mental retardation, multiple disabilities, etc. are living in the community. The "developmental twin" argument has been put forth in this context (by Tom Gilhool and others, according to Taylor et al, 1987): for any person with a given disability in an institution, there is another with the same disabilities in the community.

4) **Movement depends on availability of places rather than people's skills.** There are always "bottlenecks" in the continuum. The concept implies that people can move easily from one placement to the next as they learn new skills. This is not true because placements aren't available.

5) **The continuum concept implies that people have to leave their homes when they develop new skills.** If the system worked as it was supposed to (which it doesn't because of the dearth of skill learning opportunities and the presence of bottlenecks) people would be constantly uprooted as they learned new skills and so, moved to more independent settings.

6) **The continuum concept involves a tacit understanding that an individual <u>has</u> to progress through the different living arrangements to attain independence,** moving from setting to setting as indicated. This is seen as being too rigid, too unidirectional. People's needs are beginning to be viewed as more individualized: a person might be unhappy in a group home but, with appropriate supports, be able to succeed in an apartment. On the other hand, a person might be lonely in her own apartment and prefer the social life of a group environment.

7) **Resources are concentrated at the most restrictive end of the continuum.** Critics have noted that funds and staffing tend to go to the more institutional settings. Fewer resources are available as one moves through the continuum to more independent placements.

8) **The continuum concept emphasizes facilities not services.** One critic noted that "Every time we identify a need, we build a building". The feeling is that the field should focus on the services people require to meet their needs, rather than on the buildings in which they should be placed.

THE STATE OF THE ART IN RESIDENTIAL ALTERNATIVES

The state of the art in residential alternatives for the mentally retarded is moving beyond the continuum to more individualized, integrated and responsive services and is evolving at a rapid pace.

Ideally, the state of the art, is to find a home for people:

* with their natural family, a foster or adoptive family, or others they happen to get along with;
* in a house, apartment, duplex, trailer, condominium;
* which they own, rent or lease;
* and provide the supports they need to live successfully in the community.

In this approach, people live in *homes*, not agency owned or operated facilities. Flexibility is key. The job of the residential service provider becomes one of *identifying and providing the supports* an individual needs to be successful. These supports may be provided on a part-time or full-time basis. People are not expected to leave their homes and move on to more independent living situations as they gain skills; they stay in their homes and staffing and supports are adjusted.

The new services models are called:

* Nonrestrictive
* Non-facility-based
* Person-centered
* Individualized
* Community-based
* Housing/support services based
* Supportive living.

Ideally, in such approaches, funds are moved from supporting buildings to supporting the services that people need, wherever they may need them.

Characteristics of Innovative Models:

These innovative models, then, tend to share a number of characteristics that reflect their underlying philosophy:

1) **People live in homes**, not home-like settings.

2) **MR individuals and/or their families exercise a great deal of choice and control** in the residential settings. This may include control of such aspects as the location of the home, roommates, hiring and firing aides, menu, and schedule of activities.

3) **Service provision is individualized and flexible.** Assessment is made of what a particular individual (and, perhaps family) needs to function in his/her residential setting, which differs decisively from a group or diagnosis-related approach. The particular services a person receives, and their extent, is determined by individualized assessment.

4) **Trust is placed in the willingness and capabilities of people in the community.** Many of these programs appear to be based on the belief that, if sufficient supports and services are provided, ordinary people will be willing and able to undertake the responsibility of caring for others. A related assumption is that there are enough such people out there that *if supports are provided* they can and will take care of the problem. There is also the sense that people who have no choice as to whether they will deal with disability, such as parents confronted with the birth of a handicapped child, can cope with a great deal *if they are not left alone to do so, but are provided with needed supports that they can count on in the long run.* These programs tend to trust that families, in the main, want to do the best for their child and will choose to do so when this is made possible without destroying family life. The old alternative for families with MR youngsters - deal with the situation alone, or institutionalize - made for some very hard choices. Now, in the best of situations, the family is asked, "tell us what you need to deal with the situation and we will supply it".

5) **There is separation of housing and support services.** In many innovative programs, people with mental retardation can rent, own or lease housing and are urged to do so. Support services, as they are independent of the residential arrangement, can be provided to maintain the individual in any of these options, in any location in the community. This broadens the search for housing, rather than restricting it to certain residences. It also can

disperse people throughout the community, if programs embrace such a goal.

This separation of housing and services can open up new options in another way: Any search by people for decent affordable housing, any innovative program in this respect - co-ops, condos, etc. - can include provision for the handicapped and can sometimes get special funding or consideration by doing so. There can be a dovetailing of interests of those exploring options for low-income decent housing and those seeking housing for the handicapped.

Examples of specific programs from around the country which illustrate such approaches will be presented later in the discussion. Next, however, the discussion focuses on delineating two important aspects of state-of-the-art residential planning for the mentally retarded: permanency planning and support services.

PERMANENCY PLANNING[6]

The most innovative residential services for mentally retarded children are guided by a firm commitment to permanency planning. The premise of permanency planning is that a stable family life and enduring relationships with adults are essential to the development and well-being of children. This philosophy directs social service agencies involved in the lives of children to be committed above all else to meeting the needs of all children for a permanent family. Children are seen as having a right to a stable family; to lasting personal relationships within a home.

The concern for permanency planning for developmentally disabled children developed out of the movement for such planning for abused and neglected children. In 1980, Congress enacted Public Law 96-272, the Adoption Assistance and Child Welfare Act. According to Taylor et al (1989) this legislation was a direct response to pervasive problems of the child welfare system (which also characterize the situation of mentally retarded children in foster care). These included:

1) More children were placed in foster care and other out-of-home settings than considered necessary or

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[6] The discussion of permanency planning largely derives from Taylor, Steven J., Lakin, K.C., and Hill, B.K., "Permanency Planning for Children and Youth: Out-of-Home Placement Decisions", Exceptional Children, April, 1989, Vol. 55, No. 6, pp. 541-549.

appropriate;

2) Too many children remained in foster care and other settings too long and with little hope of either returning to their natural families or being freed for adoption;

3) Children in foster care and other out-of-home placements often bounced from setting to setting with few prospects for a stable family life.

P.L. 96-272 was seen as an important shift in federal policy away from support of out-of-home placements and toward support of home and family living. Taylor et al (1989) see this law as having had two major impacts. It established a new Title IV-E of the Social Security Act to provide federal matching funds for adoption subsidies for "special needs children" in foster care or child care institutions, as well as funds for foster care programs. Adoptive families, meeting financial eligibility criteria, could receive subsidies when adopting special needs children.

P.L. 96-272 also mandated permanency planning procedures for state welfare agencies. This procedure include the development of a written case plan, "a plan for assuring that the child receives proper care and that services are provided to the parents, child, and foster parents in order to improve the conditions in the parents' home, facilitate return of the child to his own home or the permanent placement of the child, and address the needs of the child while in foster care." It also includes a case review system, defined as procedure for assuring that "each child has a case plan designed to achieve placement in the least restrictive (most family-like) setting available and in close proximity to the parents' home, consistent with the best interest and special needs of the child".

While this legislation has had a major impact on child welfare agencies, it is seen as having had only limited influence on those dealing with disabled children. P.L. 96-272 applies only to public welfare agencies; state MR/DD agencies are not included under the protection of the law. As only about 22% of children and youth with mental retardation placed out-of-home are in "generic foster care", the great majority of these children do not come under the protection of the law, and permanency planning is not mandated for them. The authors assert in this regard:

> while permanency planning has become a central feature of child welfare policy, its influence is limited among agencies focused on developmental disabilities. Not only are such agencies not covered by P.L. 96-272, they are usually unfamiliar with the principle of permanency planning . . . (Taylor et al, 1989)

The authors point out that Medicaid waiver programs offer significant opportunities to develop programs to support children and youth with severe disabilities in their own families. However, as total state Medicaid expenditures for institutional and noninstitutional services are limited to no more than what would have been the cost of institutional services in the absence of the waiver option, states have been able to serve relatively small numbers.

Across the country, however, there are a number of agencies serving mentally retarded children and youth that can be considered innovative in this regard. These agencies embrace permanency planning as a goal and develop agency policy along these lines. They tend to see their mandate as doing whatever it takes to ensure that children grow up in stable, permanent family arrangements. Such agencies view only a small number of options as optimal for the mentally retarded children and youth that they serve. These options are:

1) **Strengthening the natural family's ability to care for the child**, avoiding placement out of the home in the first place. Comprehensive, family-defined support services are seen as the major means for this.

2) **Foster care which works toward reunification.** Historically, out-of-home placement has been viewed as permanent, with families being discouraged from continued involvement. Agencies which embrace permanency planning, feel that when out-of-home placement is unavoidable, it should be viewed as temporary. Ongoing parental involvement after placement is facilitated, and agencies use their resources to reunite families whenever feasible.

3) **If reunification is impossible: adoption.** For children unable to be reunited with their families, adoption is the option of choice in permanency planning. Once considered an unrealistic goal for mentally retarded children, recent experience suggests that adoptive families can be found for these children. The motto of such efforts is "No child is unadoptable".[7]

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[7] This cannot be said to be generally supported by state MR agencies nationwide. Such agencies are described as continuing to set up obstacles to adoption. They not only may not pursue adoption, but may actively discourage foster families from adopting their foster children. Project S.T.A.R., in Allegheny County, is in the forefront of permanency planning for handicapped children, focusing on arranging their adoption. The director of Project STAR perceives workers' attitudes as a barrier to identifying children for adoption in that they do not

Although these three alternatives are seen as optimal in terms of permanency planning, when they are not possible, those agencies embracing this philosophy may pursue other options. The goal remains one of establishing the child in permanent, stable situations that include enduring relationships with adults. Some of the models seen include:

* Shared foster care - natural and foster parents share responsibilities for the child, e.g. foster parents caring for the child during the week, natural parents on weekends; child spending part of the month in a foster home, the remainder with his or her natural family.

* Permanent foster care - a court-sanctioned or informal agreement for a child to remain with foster parents until adulthood.

* Open adoption - the adoptive family cooperates with the natural parent's continued involvement.

* Subsidized adoption.

Agencies committed to such approaches spend a great deal of time and effort on recruiting foster and adoptive parents, training them, and supporting them after placement. It is clear that this approach can't work without such commitment. It cannot be grafted as a mandate onto existing agencies who would otherwise continue work as usual, but rather must be embraced as a basic philosophy guiding policy and procedures. A number of programs based on permanency planning for mentally retarded children will be discussed in the model program section below.

SUPPORT SERVICES

A critical element which has allowed the growth of new approaches to residential services is support services to families and others. Support services are important in a number of ways. Most directly, by being provided to families with mentally retarded children, they have enhanced families' abilities to care for children. At times these services have made the critical difference between families' being able to care for their children and deciding that this is beyond their capabilities, and so, have prevented placement of children out of

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tend to see these children as adoptable. S.T.A.R. will be discussed in the model programs section below.

family homes.

In addition, the provision of such services, especially when adults living alone and with others are eligible, have enabled new residential models to be developed. The fact that support services are not linked to specific residential alternatives, but can follow individuals wherever they live, have allowed these service models to develop. Agencies have been able to be creative, placing individuals in a variety of residential arrangements and providing them with the services that they (and their families) need. Also, because eligibility for these services, in many cases, extends to adoptive families, foster families (for adults as well as children) and others, agencies have developed programs which rely on these alternatives. As we will see in the section presenting model programs, below, most of these efforts depend on the use of support services to individuals and families. First, however, we will further discuss the development and present state of support services in the United States. We will then address support services and other programs in place in Pennsylvania.

Support Services in the U.S.

In the late 1970's and early 1980's, there came a call to "stop supplanting the family and start supporting it". A variety of new federal programmatic initiatives were developed, most notably waivers and other Medicaid options, which were designed specifically to provide services in the family. The Federal Omnibus Reconciliation Act of 1981 was passed, which provided for states to request a waiver of federal regulations to provide home and community-based services to people who would otherwise be served in an Intermediate Care Facility (ICF) or ICF/MR. This opened up possibilities for a variety of support services.

Family Support Services: Core Services

The following are the most common core family support services throughout the U.S., as determined by a recent survey of the programs in operation in each of the states (Knoll, et al, 1990). The authors define family supports as those characterized by their focus on supporting the family as a whole. They do not include individually centered clinical interventions - e.g. individual counseling, nursing, speech therapy - in this category of services. These they define as "traditional developmental services", which become family supports when a state makes provision for their delivery in the home.

1) **Respite and child care** - This is the most available support service in the country, with 46 states making some provision in this area. As with most supports, there is wide variability in what is actually available to families. Some

states restrict this service to one form of respite no more than 10 days a year. Other states provide for a variety of respite options, child care support, and assistance in finding sitter services for both the child with the disability and children without a disability. Provision may be made for respite that is in-home, out-of-home, during vacations, and on an emergency basis.

2) **Environmental adaptation** - This service is provided as a family support in 32 states. Support ranges from states which completely cover the costs of making a home fully accessible, to those which partially reimburse a portion of the costs. This category includes adaptive equipment and home modification.

3) **Supportive services** - These services are provided in 27 states. They can include traditional individual counseling for parents to self-help groups including family support groups, sibling groups, and family counseling services.

4) **In-home assistance** - Provision for in-home assistance is made, in some form, in 26 states. This mode of support provides for outside assistance to help: a) in the care of the person with a disability, or b) with typical household activities so that family members can care for the disabled. Included in this mode of support are homemaker, attendant care, home health care, and chore services.

5) **Extraordinary/ordinary needs** - These are covered under family support policy in 26 states. They may cover any cost to the family that is increased because of the presence of the disabled individual, e.g. transportation, vehicle modification, special diet, clothing, home repairs. Cash subsidy or flexible voucher programs often inherently cover such costs by allowing the family discretion in how it spends its allowance.

6) **Training for family members** - Training for parents and other family members is covered as a family support in 24 states. It includes parent training which can focus on information related to the disability to information related to individual advocacy and systems change.

7) **Recreation** - Recreation is provided as a family support in 14 states. In some states, this can involve special camps and recreation programs, but more commonly it involves assisting families to gain access to recreational resources available in their communities.

8) **Systematic assistance** - This is defined as a family support services in 11 states. It includes information and referral, and advocacy activities.

Criticism of present support services:

The tremendous variability in the level of support services available in the country must be kept in mind. There are states, and areas within states, in which very little emphasis is placed on comprehensive support services, with few services available in these locations. Particular support services offered may be rigidly applied to all families, with only one or two service options available. Taylor et al (1989) assert in this context that:

> In most states, family support programs reach too few families or provide too little support to meet the existing needs. Often the services available . . . are too inflexible to meet the broad range of needs among individual families. Whereas families may have such diverse needs as physical modifications to their home, transportation, and in-home supports, family support programs are often limited to one or two services, most often out-of-home respite care.

The senior author, with different colleagues (Taylor et al, 1987) also points out that "Family support services are often operated like group homes or other residential facilities: develop the program and then find families to fit in".

The authors of the end of the decade status report on family support services conclude that "supports for families of people with disabilities are at a crucial juncture" (Knoll, et al, 1990). In general, the efforts found by the researchers in the various states were small scale and very new. They note that, although almost every state has come to the conclusion that family support is something that it should do, the direction that these efforts will take remains undecided in most states.

In comparing the commitment to family support with that to facilities-based programs, the report concludes that:

> Nationally, and in most individual states, the actual fiscal commitment to family support is a minute portion of the total budget for developmental disabilities services - facility based programs continue to absorb the bulk of the resources.

A recent newspaper article affirms this view in regard to Federal Medicaid expenditures:

> . . . of the $3.38 billion the Federal Government spent through Medicaid for the mentally retarded in 1988, the last year for which complete figures are available, 84 percent covered people in public and private

> institutions with 16 or more beds. In contrast, Medicaid spent $251 million the same year for home and community-based services for the mentally retarded. (Holmes, 10/14/90)[8]

The rationale for family support, the basis on which it has been "sold" to policymakers, is described in the end of the decade status report (Knoll et al, 1990) as being almost exclusively one of cost effectiveness; the fact that it costs less to support handicapped individuals in the community than to institutionalize them. The authors interpret this as a "crisis intervention perspective that sees the public sector providing just enough assistance to maintain the family and avoid the demand for an expensive out of home placement". They feel that the basic message of family support is, rather "about the ultimate reconfiguration of developmental disabilities services away from facility-based models to a *true* community system".

In terms of progress toward this perspective, the authors note that "the last decade has seen most states make the decision to get out of the business of running large congregate care institutions". Based on their findings, they conclude that "within the next decade each state will confront another fundamental decision about its policy direction". The question that will face policy makers is stated as being:

> "Will we continue with business as usual, placing our primary emphasis on funding programs and facilities and providing minimal support to families and adults with disabilities who live outside our facilities, or will we shift to a truly individually driven system in which we fund the unique constellation of services and supports that each person needs?" (Knoll et al, 1990)

<u>Innovative approaches to support services</u>:

As with the residential models, there is some evidence of more novel approaches to support services from around the country. More innovative approaches see every family as different and base services on the needs of specific families, as they themselves define those needs. Such programs undertake to

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[8] Further analysis of these figures indicates respective Federal Medicaid expenditures to be:
$2.84 billion, 84% - institutions with 16+ beds.
$251 million, 00.07% - home and community-based services.
Expenditures for institutions is, thus, <u>1200 times</u> that for community-based services.

provide whatever is needed to maintain and enhance the family's capability to provide care at home. Also, the definition of what constitutes a family is usually very broad. These programs then, are flexible, comprehensive and allow families to define the support services that they need.

A number of factors appear to determine whether a system is one in which families personally define, and are able to meet, their support service needs: whether financial assistance or service vouchers are given directly to families, the degree to which funds or vouchers are restricted to particular uses, and the range of publicly subsidized services available. A number of programs stress that they are "family-centered" or "family-defined". (Pennsylvania initiative's in this regard, "Family-Driven Family Support Services", will be discussed below.)

Taylor et al (1987) identify a number of states and communities that have developed innovative approaches to supporting families based on the individual needs of the families themselves. The authors consider the best services to be those that are flexible and individualized, build on informal supports and existing social networks, and place control in hands of families. They describe three innovative approaches currently in evidence:

1. Smorgasbord approach:

In this approach, families are provided with an allotment with which to purchase one or more types of respite from a "menu" of services. One program that uses the smorgasbord approach is Community Services for the Developmentally Disabled, a community mental health center in the Clinton-Easton-Ingham counties area of Michigan. This program provides families with $255 worth of respite per quarter (every three months) in addition to family subsidies from the state. Families can select from the following:

a) Foster home respite care - respite care in licensed foster homes by providers who are trained individually to work with the child. After training is provided, the family makes arrangements with the provider directly. Cost of services: $20/full day, $10/half day (up to 6 hours).

b) Home-based respite care - respite care provided in the home by a part-time agency employee who is trained to work individually with the child. Arrangements are made directly with the worker. Cost: $4.50/hour, up to 16 hours/day.

c) Family friend respite care - respite care provided by a person selected by the family and paid $2/hour with a maximum of $15/day.

d) Drop-in day care center - "first come, first served" drop-in center operated on Saturdays from 8:00 a.m. to 10:00 p.m..

Eight spaces are available. Cost: $2/hour.

Families may be able to exceed their quarterly allotment in the case of emergencies if they receive prior approval. Families can also use their own funds to purchase additional respite care services.

2. Voucher system

Taylor et al (1987) point to Wisconsin as having one of the most innovative family support programs in the country. It stands out for its responsiveness to the needs of individual families: flexible, individualized and "family-centered". Wisconsin's Family Support program is administered by counties, with approximately 1/3 of counties participating. Counties may either provide services directly or contract with local agencies.

The program provides up to $3,000 (presumably per year - the authors do not specify) in services for families with members with severe disabilities. The state is authorized to approve additional funds to families upon the request of local administering agency. Under state legislation, 10% of funds allocated to a county may be used to pay for staff and other administrative costs; the rest must be used directly for family support services.

Families' first step in participating in the program entails receiving a needs assessment and family plan. To be eligible, families must have a child with a severe disability according to state criteria. There is no income test for the program; however, families may be expected to share some of the costs of services. Under state legislation, a child is defined as being under the age of 24. In practice, however, the program is directed at families of children in school and the state must approve services for children 21-24 years old.

The needs assessment looks at the family's existing formal and informal support networks. The family plan attempts to build on these. For example, a neighbor may provide transportation for a child. The plan specifies what services a family will receive through a program. Services may be paid for directly by the agency or the family can be given a grant to pay for them with the family being required to keep receipts.

The program lists 15 specific categories of services a family can receive. These encompass a wide range of services including: architectural modification of the home, child care, recreation, transportation, vehicle modification, homemaker services, attendant care, home training and parent courses, respite care, and specialized utility costs. Other goods and services may be approved by the state. In addition to providing support services, the program makes provision for a family support coordinator or case manager to act as a service broker, helping to coordinate other services the family may need, e.g.

generic community services such as recreation programs, medical and dental care, and public transportation.

3. Cash subsidy

Michigan is one of the states with a family subsidy program. In this program, the state pays direct cash subsidies to families of children with severe disabilities. The subsidy is designed to help families pay for the extra expenses incurred in having a child with severe disability, e.g. equipment, respite, home renovation, diapers, sitters. The subsidy amounts to $225/month, $2,700 annually for eligible families.

Taylor et al's (1987) discussion of this program appears to indicate that families can spend the money any way they wish, although this is not explicitly stated. Opponents of the legislation are described as "taking the position that families would be better off by providing the funds to the agencies to operate family support programs" and questioning whether families "might use the funds for other things not related to their children with disabilities." Supporters are described as feeling "that families themselves were in the best position to determine their needs" and as making "the assumption that families are capable of making good decisions." The authors also add that "it might be argued that even if families used the subsidy for general household expenses, this can make it easier to maintain their children at home". Whether the families have to furnish receipts to indicate expenses is not stated.

The authors see this program as an important step in the right direction in that it encourages, rather than discourages, families to maintain their children at home. Over 2,000 families are described as participating in the Family Subsidy Program throughout the state of Michigan.

Comparison of the advantages and disadvantages of cash subsidy and voucher programs:

The degree to which restrictions are attached to cash subsidies, in terms of allowable service purchases and required receipts, determines the extent to which disbursements are defined by the family. If purchases are largely unrestricted and receipts not required, cash subsidy can put ultimate control in the hands of the family, which determines totally how it spends this money. The absence of checks on family expenditures also allows program bookkeeping to be kept to a minimum. (The philosophy in such programs is that the family knows best how to spend its money and that any purchase made, even if it does not appear to directly relate to the handicapped member, will ultimately benefit him or her. It also clearly involves a strong element of faith that the family will spend its money wisely.) Cash subsidy programs which restrict purchases and require receipts to prove how money was spent are probably closer to

voucher programs in philosophy and impact. Voucher programs point to their advantage over those involving cash subsidies as being one of greater accountability; they ensure that the funds are expended on purchases directly related to the handicapped family member. Another advantage of voucher over cash subsidy programs, in the view of the director of the Wisconsin program (cited in Taylor et al, 1987) is that this approach adds an additional dimension by putting the family in touch with a case coordinator who can help it, should the family want this.

SERVICES AND PROGRAMS IN PENNSYLVANIA

The Commonwealth of Pennsylvania evidences examples of each of the programs and services for the mentally retarded that have been discussed. The state makes provision for family support services, family-driven support services and family living for this group. Permanency planning has also been established as a goal, although it is not clear how far program and practice have moved toward this objective. This section will outline relevant services and programs in the state[9].

Pennsylvania has a Medicaid waiver program, under section 1915 (c) of the Social Security Act, establishing services to eligible persons who would otherwise require the level of care provided in an ICF/MR. State funding may be authorized for payment for families serving children who would otherwise be institutionalized. Families may also be reimbursed for services

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[9] The section describing Pennsylvania's services and programs is based on the state program summary presented in Knoll, James A. et al, Family Support Services in the United States: An End of Decade Status Report, Cambridge, MA.: Human Services Research Institute, 1990, and on material received from the Pennsylvania Office of Mental Retardation (OMR). OMR material includes: Chapter 6350: Family Resource Services, Chapter 6400: Regulations for Community Residential Mental Retardation Facilities; Mental Retardation Bulletin 00-89-09, "Request for Proposals to Develop or Expand Family-Driven Family Support Services Pilot Projects, 4/19/89; Mental Retardation Bulletin 00-90-21, "Approved 2176 Waiver Renewal", 7/1/90; Mental Retardation Bulletin 00-90-04, "Fiscal year 1988-89 Annual Report" 2/23/90; Mental Retardation Bulletin 00-90-15, "Family Living Guidelines", 5/1/90; personal correspondence with Dana Olsen, Section Head, Policy and Program Development for Residential Services, 9/20/90, and personal correspondence with Arthur R. Geisler, Section Head, Policy and Program Development for Non-Residential Services re: Family-Driven Support Services, 7/27/90.

provided for adults using State and Federal funds under Medicaid.

Permanency Planning

The approved waiver renewal makes provision for permanency planning for mentally retarded children, defined as "the systematic process of carrying out, within a time limited period, a set of goal directed activities designed to help children live in families that offer continuity of relationships with nurturing parents or caretakers and the opportunities to establish lifetime relationships." Services outlined in the waiver renewal include:

- identification of minor children in ICF's/MR and residential settings who are at risk of institutionalization and are lacking a permanent family relationship or who are at home and at risk of institutionalization,

- assessment of these children and their parents and development of a plan for family permanence with the birth family, or if this is not possible, for extended family, family living or adoption as permanency options,

- post adoption support for up to one year after adoption is subsidized.

Eligibility is limited to MR children age 18 or under who are residents of ICF's/MR, or who are at risk of institutionalization in an ICF/MR. Neither specific examples of programs directed toward permanency planning, nor an estimation of the extent to which these guidelines are being followed across the Commonwealth, is available. It is clear, however, that family support services and family living programs *could be used* to effect permanency for children who meet the eligibility requirements. The degree to which they are directed toward that end, and the extent to which, for example, lists of minor children in ICF's/MR are reviewed for that purpose, is not clear. An agency in Pennsylvania directed specifically toward permanency planning, Project S.T.A.R., will be discussed below.

Family Support Services in Pennsylvania

* Name of program: Family Resource Services

* Number served: approximately 16,000 families

* In operation since 1972

* Eligibility: Persons with MR who live at home with

biological or adoptive, foster families, relatives or legal guardians. Persons living independently in the community may also be eligible.

* Wide range of services, which include: respite, therapies, homemaker services, financial assistance, home modification, parent training, recreation, sitter/companion, special diets, adaptive equipment, behavioral programming.

* Current funding level: approximately $12 million for the 1989/90 fiscal year.

* Funding is 90% State/10% County matching.

* Services are provided based on:

  - individual family need

  - available funding

  - particular county's ability to provide support.

The status report's evaluation of Pennsylvania's family support program notes that quality varies from county to county: Some counties are totally committed and have funded a good system of service providers and developed community resources for families. In other counties, family support is not a high priority and the availability of services is not widely known. The evaluation also notes that additional respite care and increased therapies are needed by families statewide and that services to families with a member with a disability other than MR are minimal.

New PA Initiative - Family-Driven Family Support Services

According to the state Office of Mental Retardation, Pennsylvania is currently involved in a new initiative directed at developing programs that recognize that families can play a more significant role in planning, implementing, evaluating and setting priorities for family support services to address their specific needs.

Family-driven support services are defined by the state as those in which:

* The family and the person with MR, rather than the service system, are given the responsibility for deciding which services will best address the family's specific needs.

* Family members also have a primary responsibility for planning, implementing, evaluating, and setting priorities

for services to address their specific needs.

Pennsylvania's OMR currently proposes four suggested models of these services:

1) **Cash payment** - provides cash payment directly to family. Family may use money only for services eligible under the MH/MR act of 1966.

2) **Voucher** - a voucher is used for payment for services, or payment made to the family after submission of receipts for services.

3) **Traditional Funding/Preapproved Service Plan** - the family is allowed a certain amount of services based on an annual need review and prearranged plan. Payment is made by the county or a designee. The family receives no money or vouchers to purchase services.

4) **Informal supports/Community organizer** - funding a community organizer to develop a system to provide services, materials or financial assistance for the family through friends, relatives, or community groups. e.g. Service clubs, church groups provide friendly visiting, shopping assistance, respite care co-ops. Informal supports would be provided in addition to, not as replacement for, traditional services.

Eleven family-driven family support services projects were initiated in Fiscal Year 1987-1988; 15 in 1989-90. As two of the projects funded in 1989-90 were expansions of projects from the previous year, there are currently 24 pilot projects underway, in 23 counties (Philadelphia county has 2). A number of projects incorporate combinations of the four service models discussed above. The projects are reported to be serving somewhere between 2247 - 2867 individuals, and, according to the state office, may be serving larger numbers.[10]

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[10] More projects of this type may be in evidence than those listed by the state. The deputy director of Allegheny's MH/MR agency reports that it has three pilot projects of this type, that are not on the state-wide list. Each of these involves a different approach. One of the Allegheny county projects involves use of community organizers who so far have apparently had the effect of getting parents to demand more services. They will be trying to work toward mobilizing natural support systems - e.g. neighbors, church groups - to be involved with these families. Evaluation of these programs will involve measures of family satisfaction, pre- and post-program. (Personal interview with Firth and Fascio, 1990)

According to OMR, a state-wide evaluation of the family-driven pilots has been done but results are not yet available. The end of decade status report on family support services (Knoll et al, 1990) states that a survey of families participating in family driven pilot projects in Pennsylvania show they have been extremely pleased with services received. They reported: relief from stress of caretaking, ease of financial burden, benefits from contact with other families, much appreciated time away, and satisfaction with the flexibility of support. The status report describes Pennsylvania's OMR as planning to continue to make the system more responsive to families' needs by conducting area-wide public meetings to get direct input from families about the direction to take. It is also described as hoping to see family support services more equitably distributed within the state with a better understanding at the local level of the efficacy of supporting families in their role as primary care giver.

Pennsylvania's Family Living Program

* Definition: A family living home is an arrangement in which an individual with a disability joins another individual or family in their private home as a fully participating member. The family living arrangement allows the sharing of food, shelter, experience, responsibilities and love. The individual with a disability contributes, shares and receives needed care and support from the family and through community services.

* The program was introduced in 1981, as a pilot project in Berks County for 15 people from Hamburg Center.

* It is a community residential services option in which 1-2 individuals with MR, are provided with services in the home of an unrelated adult or companion.

* A family living coordinator is responsible for providing support and direction for families and for ensuring that services are provided in an appropriate manner. The coordinator also works with outside agencies on issues relating to the resident's program and care.

* As of 8/1/90, the program was described as involving approximately 25 counties and 250 people in family living homes, with both adults and children served.

Other residential support programs in operation in PA.

* According to a 1989 survey of County MH/MR programs, over 2,000 individuals with MR are residing in generic

programs that involve family living.

* These are different from Family Living, above, because of their funding source, eligibility criteria, and program standards.

* Examples of these generic services also used by individuals with MR: foster family care for children, adoptive families, dom care for the elderly, and personal care homes.

INNOVATIVE RESIDENTIAL MODELS FROM AROUND THE COUNTRY

The discussion will now turn to programs visited by the Center on Human Policy, University of Syracuse. The Center conducted a national search for model programs which strive to integrate people with severe and profound mental retardation into their natural communities. After information was collected by mail and telephone, programs were selected for site visits of 2-3 days. The resulting project reports were invaluable to the present information-gathering effort, allowing this researcher to be an armchair traveler, reaping the benefits of widely-scattered visits to the field without leaving home. The site visit reports are exactly the type of material that the present author envisioned discovering in the course of pursuing this research - detailed descriptions of innovative programs and practices of residential services to the mentally retarded across the country. The discussion will now turn to descriptions of a number of programs explored by the Center on Human Policy, taken from site visit reports.

Site Visit 1: Community Living in Three Wisconsin Counties[11]

Options in Community Living:

* This program supports approximately 100 people in the community, in apartments and houses that they rent.

* Both mild and more severely impaired individuals are served.

* 17 people have live-in staff, providing full-time support.

* Some clients hire their own staff ("attendants") for which Options acts as a broker. It recruits, trains and works with clients to help them learn to supervise their own attendants.

* In some cases, Options uses foster care funding and licensing to arrange for "paid roommates" who provide companionship and support. An example of this: two men who had been living in an institution, now live in an apartment with a paid attendant. The attendant is a college student who is supporting himself through school, earning $800/month. He has two weekdays and two weekends off a month. Relief staff come in when he's off. The lease for the apartment is in the names of the two men with disabilities. Apartment expenses are split three ways.

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[11] Taylor, Steven J., Site Visit Report: Community Living in Three Wisconsin Counties, Center on Human Policy, Syracuse University, 1987.

Additional supports are also provided to the men.

* The site visit report felt that Options was one of the most innovative and responsive agencies in the country. What was reported as making it so responsive to its clients was, first, the fact that it is committed to community integration, individual autonomy and quality of life. Also, it is a small, human-scale organization, free of bureaucratic trappings. The agency has decided to limit further growth, fearing that expanding its services would compromise quality. The program's success is also ascribed to its being open to change, flexible, inviting external review, and taking recommendations and suggestions for improvement seriously.

Columbia County:

* This county contracts with a small private agency to support people with disabilities living on their own. The agency hires support workers or "friendly visitors" recruited from the local neighborhood to provide support to people for up to 20 hours per week at minimum wage.

* The county also sets aside funds for people living on their own to deal with the expenses of setting up a home. It has set up a closet of materials, with a lot of things being bought on sale. Clients can use or rent things from the closet such as: dishes, brooms, t.v.'s and bikes. The director is quoted as feeling that, "When people start out, they have a lot of front-end expenses. You have to have some stuff available so they can live." The director also indicates that the county has "a pot of money to help people with things like security deposits. We'll put down a security deposit and they pay us back over time".

Site Visit 2: Professional foster homes and supervised apartments: Washington County, Vt.[12]

Professional foster homes program:

* Also called: professional parents program, professional development homes.

* Program serves 40 clients who live with families in the community.

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[12] Bogdan, Robert, It's a Nice Place to Live: Professional Foster Homes and Supervised Apartments in Washington County, Vermont, Center on Human Policy, Syracuse University, 1986.

* Clients have severe disabilities and range in age from 6 to 63, with a mean of 16. 25 are children; 15 are adults.

* At least one parent in the home must have an undergraduate degree with some graduate training, preferably in the human services, plus experience in education or human services.

* Participating families develop goals and objectives for the people living with them.

* Parents are provided with individual consultation and supervision, and other support.

* Support staff and respite care is available. The professional parents have a network to help each other. All services are provided in the home or by generic local agencies.

* Most parents are husbands and wives living together with children. There are also two single people of the same sex.

* Many of the providers either work for the agency, with their spouse taking on major care responsibilities, or are in some way related to the agency.

* The families receive $11,000/year tax free for each child.

* The advantages for this program were seen as being:

  - The person becomes part of a family and the family is part of the community, so client naturally makes contacts that integrate him or her into community life. In most other models the client can remain isolated within the agency.

  - The client is exposed to more appropriate models while having the benefits of attention.

  - The home does not rely on agency services and can be located in wider geographic area.

<u>Supported apartments program</u>:

* People with developmental disabilities, some severe, live in dispersed apartments, no more than two per apartment.

* There are two types. In one, a staff person stays the night. In the second, clients sleep alone. In both, the apartment is considered the clients' with the staff and outsiders as guests.

* The advantage of this program is seen as being that the staff can change their level of involvement in residents'

lives. Without having to move, disabled adults can go from having a staff member staying with them for the night, to being on their own.

Site Visit 3: The No Name Program, Burlington, Vt.[13]

* This is considered an extended family concept.

* In this situation, three very disabled people live with a family. The clients are in their mid 20's, have been institutionalized for long periods of their lives and have significant health and behavior problems. The description makes clear that they are very disabled.

* The mother of the family has no outside employment; the father works half-time at the university. There is also a network of friends and associates involved with the house.

* Two people are paid to come to the house in the late afternoon on weekdays, staying until the three disabled individuals are asleep. Two other staff live in the house on the weekend, as the family usually leaves every Friday night, returning Sunday night.

* The clients are in a day program 6 hours daily.

* Half of the money for the program comes from Medicaid, the other half from the state of Vermont. The cost is about $40,000/person/year. The cost of caring for these individuals is noted to have been higher in the institution in which they lived prior to this arrangement.

Site Visit 4: Family Supports in Montana[14]

* The program takes place in Region III, which is made up of 11 counties. It is a rural area covering approximately 140 square miles and includes the Crow Indian reservation.

* It is called specialized family care.

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[13] Bodgan, Robert, The No Name Program: Three Severely Multiply Disabled People Who Live at the Petrone's in Burlington, Vermont, Center on Human Policy, Syracuse University, 1986.

[14] Walker, Pam, Family Supports in Montana: Region III: Special Training for Exceptional People (STEP), Center on Human Policy, Syracuse University, November, 1989.

* The program's stated purposes are:

  - to prevent placement out of the family settings for children with intensive needs, and

  - to create movement to family settings from more restrictive environments.

* Services provided include: home training, in-home assistance, occupational therapy, physical therapy, architectural modifications, adaptive equipment, full-time foster care, shared foster care, extended respite.

* The program is funded through both Medicaid waiver and state dollars. Eligible: individuals 0-22 years old, developmentally disabled, at risk of institutional placement. At risk is defined as: severe/profound MR and/or those with environmental factors such as stressful family situation.

* There are 73 slots statewide.

* The average cost per family cannot exceed 80% of the average annual group home cost per child in Montana, $25,000. In Region III, the average annual cost/family is stated as being $10,400, significantly below the 80% figure of $17,000. As of 7/87, there were 16 children served in this program in Region III.

* Examples were given of shared foster care arrangements made through the program. In some cases, children spend from 2 to 5 days a week out of the natural home, in a foster family home. In one case, an 18 year old with MR, severe cerebral palsy and a hearing impairment lives with her father two weeks a month, in a foster home the other two weeks a month. The foster mother works at the girl's school, has her own hearing impaired daughter, and lives three blocks from the father. In such arrangements, natural families are described as participating in the selection of foster families.

* For respite care, families are described as tending to hire friends, relatives, and neighbors. Pay for respite care is noted as being very low.

FOUR INNOVATIVE PROGRAMS

We will now focus on four specific programs that were discovered in the data gathering process that combine a number of interesting elements to create innovative housing options for the

mentally retarded. The first three have in common the development of permanent housing arrangements in the community, to which supports are then provided. The fourth is a unique program focusing on permanency planning for disabled children, which is located in Allegheny County.

Family Consortiums, Ohio[15]

* In this program, parents or guardians of developmentally disabled individuals - adults and children - form a consortium which serves as an administrative body managing a certified home in which the disabled individuals reside.

* The consortium purchases, rents, or leases a home. That home is considered an extension of the family home.

* The program was started by 3 people: a parent, a superintendent of a county board (In Ohio, each of the 88 counties has a County board of MR/DD.), and a private residential provider, who approached the Department of MR with the idea of a pilot.

* The members of the first consortium established themselves as a non-profit and set up a situation in which five adult women live in two apartments.

* In this program, the maximum number of individuals permitted in one home is four. However, a consortium may administer more than one home. A variety of housing options and roommate "groupings" can be pursued.

* An important aspect is that staff are selected by the consortium, which is solely responsible for their hiring, firing and evaluation.

* At present, the program is in its third year. Eleven new projects are expected this year, making a total of 19 projects by the beginning of 1991.

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[15] Sources of information on the consortium project were: Blazina, Ed, "Experimental Consortiums Run Group Homes in Ohio", Pittsburgh Press, 6/26/89.; The Ohio Department of Mental Retardation and Developmental Disabilities, The Family Consortium Pilot Project, Report to the Ohio General Assembly, 4/89; The Ohio Department of Mental Retardation/Developmental Disabilities, Family Consortium Project, Bureau of Residential Services, 9/19/89; Project brochure: "Family Consortium Project: Like an Extension of the Family Home"; videotape: "No More 353", Ohio Department of MR/DD; and telephone interviews with Terry Wallace, Deputy Director, Ohio Department of MR/DD and Vicki Grosh, Project Director.

* One of the existing consortiums is for children. Three children live in a house that is within 5 minutes of their family homes. Two of the three families purchased the home; the third pays rent. A county board employee was appointed a member of this consortium. There are one full-time live-in, and four part-time, staff in the home.

* There are a number of factors common to all the consortiums:

  - All rotate responsibilities among the parents.
  - All families rotate being "on call" for emergencies.
  - The adult clients are involved in decisions such as staff hiring/firing.
  - All consortia decide staffing patterns.
  - Parents help cover shifts when a staff person is not able to work, providing direct care (without pay).
  - All homes are certified by the local county board, not licensed by the state department of MR.

* The program feels that the guiding force that makes it unique is the intense involvement of the family/parents and/or friends. The parents assume the roles of: administrators of a home, supervisors of employees, managers of state funds, negotiators with other parents and "on call" crisis intervention persons.

* The program is clearly not for everyone. Program material describe it as designed to support families who want to maintain frequent contact with a son or daughter, yet want to provide a living situation for their children outside the family home to allow that person to grow and gain needed autonomy and independence.

* Among the advantages to clients are that they remain in their home communities, and choose their roommates.

* The program is reported to cost the state less money than group homes. Each individual living in a home run by a consortium costs the state $25/day, rather than the $75/day cost of a group home.

* Funding sources for the consortiums include:

  - the state
  - the families, which pay $300/mon for expenses such as rent and food
  - local, county Supported Living funds
  - private donations
  - clients' SSI.

Shared Housing for Special Populations Project: The Resource Center for the Elderly, Ill.[16]

* The shared housing movement involves individuals seeking a place to live being matched with those who are willing to share their homes in exchange for rent and/or services.

* Such programs have been typically developed for the elderly: Elderly individuals who own homes are enabled to remain in them by being matched with individuals who share the home and help with expenses and chores.

* Shared Housing for Special Populations matches adults with developmental disabilities with community residents to live in mutually beneficial shared living arrangements.

* In exchange for living space, support is provided for the homeowner in the areas of finances, and/or assistance with housework, cooking, yardwork, errands or companionship.

* Program operations:

  - Each applicant is personally assessed and interviewed.

  - Potential homesharers are introduced.

  - If both consent, a custom-made agreement is developed to reflect the mutually-agreed-upon conditions of the match.

  - Support is provided during the transition by community volunteers, by mapping out homesharing logistics, and by creating an awareness of community resources.

  - There may be 6-8-10 months of preparation before the homeshare actually takes place.

  - Skill training occurs. Professional staff provide support services and training for the duration of the match in the areas of socialization, money management, community resources, cooking, etc.

* There is a monthly support group for parents and individuals in the program, which meets to discuss a topic of general interest.

* There have been 3 matches made in the program since January,

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[16] Information on this program was gathered from project materials obtained through the program itself, which included program brochures and a detailed letter from Gwen Rosenblatt, Project Director.

1990, with more reported as imminent. There have been 6 such matches since the program started two years ago.

* Clients in the program have mild to moderate MR or cerebral palsy, are self medicating and do not require 24 hour/day supervision.

* The homeowners are described as people in their 20's to 50's, mostly in their 30's to 50's. The handicapped individuals are mostly in their 20's and 30's. Interest in the program by students aging out of the school system, 23-24 years old, has been noted.

* The motivation of the nondisabled home providers for participating in the program are described as being altruistic and financial. One couple in their 30's was noted as having considered having foster children but feeling they couldn't commit to the required time. They are quite satisfied with their present arrangement of having a mildly retarded man in his 30's living with them, feeling that they are contributing to society.

* The relationships established by the program are described as being "more like roommates than family". (Contrast this with family living and adult foster care programs described above.)

Prairie Housing Cooperative - Winnipeg, Canada[17]

* 1982, a community of people banded together to cooperatively own their own homes and to live as good neighbors and friends in five neighborhoods across the city.

* The co-op originally developed in response to the needs of one man who needed to leave an institution. A group of people arranged for a house, money and staff. Gradually the group grew and the idea emerged of helping people establish their own homes through a housing co-op. A search lead the group to the Social Housing Program of the Canada Mortgage and Housing Corporation (CMHC), which subsidizes mortgages for co-op homes, providing, in effect, a low-interest loan. The Manitoba Department of Cooperative Development helped to establish the structure of the cooperative, and the Winnipeg Regional Office of CMHC helped the co-op purchase its first 18 units of housing.

* How the program works:

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[17] Kappel, Bruce and Wethrow, David, "People Caring About People - the Prairie Housing Cooperative", Entourage, Vol. No. 4, Autumn, 1986.

- Over 4 years, 20 individual houses and townhouses were purchased and occupied by the community. Unlike most other housing co-ops, homes were dispersed throughout the community.

- In each case, homes were bought with specific members in mind and located according to members' wishes. In each neighborhood, the co-op purchased "clusters" of 2 to 4 neighboring houses or apartment units. One unit in each cluster is occupied by someone who needs extra assistance.

- No more than 2 people with handicaps live in any one household. Families and individuals without handicaps are recruited to live in nearby co-op houses or to share a house with a person who has a handicap. They are encouraged to form relationships with other co-op members, especially those who are challenged by handicaps.

- Organizers rely heavily on informal and natural supports between members. The relationships are voluntary, and housemates share equally in household expenses.

- For some of the members who have handicaps, arrangements are made for non-handicapped people from outside the co-op to provide support. In a few cases, when someone needs assistance which is difficult to provide on a voluntary basis, a housemate or other support person is employed through special project grants or government program.

* By the of fall 1986, the program involved 60 people living in 20 households; 12 of these had mental handicaps. The co-op reports that its handicapped members find many of the supports they need in the co-op and have control over the important decisions in their lives.

* Everyone, with and without handicaps, is described as having joined the cooperative for the same reasons: wanting decent and affordable housing and a chance to be part of a close-knit community.

* Program literature describes handicapped individuals sharing their homes with nonhandicapped roommates who help them with their daily life. Also pictured is a family with a young, very handicapped child. The family is described as being provided supports for child by two other co-op households in the neighborhood, which the family itself played a large role in selecting. ("One is a longtime friend who knows child and her family well. She understands their needs and is willing to offer practical help such as exchange babysitting".)

* The initial organizers set out to ensure that people with special needs could live in decent housing with control over their tenure in their own homes, and that they would have the freely-given support of close friends and neighbors.

* People with handicaps are described as being involved in fundamental decisions about their lives, including with whom they live and the management of their households and their cooperative. People who might have a great deal of difficulty in expressing their views, are co-represented by family members.

* Handicapped co-op members are reported as being satisfied that they could live with people of their own choosing, either by remaining with their families or by forming new families and relationships. In group homes and institutions, they said, you can't choose your housemates or roommates.

* Cooperative organizers stressed the interdependence of members with and without handicaps rather than fostering one-way dependence. The underlying philosophy appears to be that natural relationships - and enough of them to provide a sense of continuity and security - give members with a mental handicap a sense of belonging in the neighborhood and the community.

* There appears to be more of a tradition of, and more established supports for, housing cooperatives in Canada than in the United States. The question remains whether this model is worthy of further testing in this country, and is, indeed, transferrable to the U. S..

Project S.T.A.R. (Specialized Training for Adoption Readiness) Permanency Planning Advocates of Western Pennsylvania[18]

* There is an unusual agency in Pittsburgh, probably the only one of its kind in the U.S. It is currently located in a small house on the grounds of the Rehabilitation Institute of Pittsburgh in the Squirrel Hill neighborhood of the city.

* S.T.A.R. is an adoption agency for children with disabilities, the only such agency that focuses on such children in the U.S.

* Almost all children placed by this agency have an MR involvement - approximately 98%. It has placed children who

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18 Information on Project S.T.A.R. was obtained from project materials and from a personal interview with Susan Maczka, Project Director.

are profoundly MR.

* S.T.A.R. began in October 1985 from a grant awarded by the PA Developmental Disabilities Planning Council. It was a collaborative effort of 3 agencies: The Rehabilitation Institute of Pittsburgh, Three Rivers Adoption Council and Allegheny County CYS. Each agency contributed expertise, in kind services and other supports. The project has a 5 member staff. Funding comes from state and foundation grants.

* S.T.A.R. has placed 55 children since that time. These children have been referred from agencies in Allegheny, Westmoreland, Butler, and Beaver counties.

* Referrals tend to be children in institutional settings, and foster homes. Caseworkers in the CYS or MH/MR systems are asked to look at their caseloads, for potential referrals.

* It might be assumed that the agency would be flooded by referrals, by names of MR youngsters who need homes. On the contrary, S.T.A.R. describes itself as having trouble getting names, as workers don't consider these children adoptable. The agency feels that worker attitudes are a major barrier. MR youngsters were not and are still not considered adoptable.

* The children tend to have had numerous placements. The agency has dealt with one 4 year old who has had 23 placements. On average, children have had a minimum of 4 placements. 80% of the children have been sexually abused, either in their natural home or in a placement.

* S.T.A.R. has placed children from birth to 18 years old; the majority are 2-8 years old. Age tends to be a factor in adoptability, with the agency doing better with younger children.

* These cases are often a legal risk for adoptive parents, in that parental rights may not be terminated. What occurs at times is that the parents themselves are mentally retarded or have a severe emotional disturbance. The agency has to work on relinquishment so that these children don't languish in institutions.

* S.T.A.R. spends a lot of effort on recruitment of families. All kinds of methods are used - the different media, and now, considerable word of mouth. The agency prides itself on knowing their children well. S.T.A.R. considers itself an agency for children, not for prospective parents. (The director made clear that S.T.A.R. will not search the country for a particular couple's dream child.) There are a number of parents who have adopted more than one child.

* Parents receive training, consisting of nine weekly sessions, including a sibling night.

* S.T.A.R. offers on-going support and contact for those families who wish it (some don't). The agency gives four big parties a year, attended by over 100 families. It offers community workshops for families on topics such as estate planning, sexuality. The parents also receive a newsletter.

* S.T.A.R. states, in regards to its adoptive families, "We're here for them indefinitely." There are presently cases in which the agency is helping to pay for therapy for children found to have been victims of sexual abuse years after adoption.

* Adoptions can be arranged as open adoptions, with birth families continuing to have contact.

* Families are paid $200-300/month per child until the child reaches age 18. Children also receive Medical Assistance.

* In addition to arranging adoptions, S.T.A.R. describes itself as very concerned with other aspects of permanency planning. The agency and would like to see fewer children placed out of their natural homes in the first place and greater efforts to reunify children with their families if they are placed.

* A new effort in this direction is a pilot program to aid mothers in keeping their children. The agency has its first case at present: a young mother from a public housing project with two other children who was overwhelmed by the birth of a handicapped child. S.T.A.R. is now providing a host home for the baby, with an experienced foster mother. This is planned to be a temporary situation. The mother visits every day and will eventually take the child home.

* S.T.A.R. has also recently become concerned with young adults, 21 years old, living in children's homes who are becoming too old for these situations. Some have never lived with anyone but paid providers. The agency is currently exploring the possibility of identifying these individuals and determining whether they can be placed in family living situations.

* S.T.A.R.'s goal is "No child in an institution".

CONCLUDING REMARKS

Much of the material in this report was recently presented to the annual conference of the Pennsylvania Association of Rehabilitation Facilities (PARF), to an audience of professionals working in rehabilitation facilities of various kinds. At the conference, it became apparent that the state Office of Mental Retardation strongly endorsed these community-based approaches and was urging agencies to move in their direction. The professionals attending the session appeared to be grappling with the implications of this for their agencies' programming and their own professional roles. They were especially interested in learning about specific program models.

The new initiatives appeared to be generally supported by the individuals at the presentation. Of interest, however, are the reservations expressed by those who were less than enthusiastic. A number were somewhat wary of models using foster or host families for mentally retarded individuals. Concern was raised about the qualifications of most of these families to carry out such specialized work and about potential turnover in the system. The feeling seemed to be that without adequate assurances as to qualifications of caregivers and stability of arrangements, such programs would be apt to experience the same problems as the child foster care system - e.g. frequently changing, insecure placements, poor care, and even abuse at the hands of caregivers.

Such concerns can help to indicate areas that will require attention should such models become the prevailing norm. Programs can clearly lose important elements in the translation from limited demonstration to widely applied alternative. A typical demonstration program handpicks both clients and caregivers for their suitability to the program model. Dedicated staff, committed to program success, are responsible for supervising and supporting the resulting arrangements.

Once a program becomes an established alternative, problems of increased scale and familiarity can tend to lessen its effectiveness. Clients who are not particularly suited to the program are referred. The need to recruit large numbers of families means that they can't be held to the same standards as those in the pilot group. Program staff may have no vested interest in the program, viewing it as simply another alternative imposed from above. The novelty factor also wears off with time; the program is no longer new and exciting and simply becomes one among many.

This is not to say that pilots and demonstrations are not important for developing valuable new program ideas that can be translated to other settings. The point is, rather, that one has

to be aware of and make provision for potential dysfunctions of scale and familiarity. To increase the chances of success and avoid these potential pitfalls, programs must, preferably, be kept small, or, if this is not possible, be careful to build in safeguards. For instance, family care programs should be limited to those clients that are truly suited to them, and should remain very particular about caregivers, staff and supervision. (This also implies that a sufficient range of alternatives is available to permit consumers not suited to one to be accommodated in another.)

It is likely that an essential component of some programs is their limited scale in which intimacy of contact with clients and living situations, by handpicked, dedicated staff, is assured. Such programs are not apt to retain their effectiveness if transferred to large, impersonal settings. Careful consideration of such integral elements might allow alternatives such as family living to be successfully implemented on a wider basis and help them avoid the pitfalls of traditional foster care systems.

This report has discussed new approaches to residential and support services for the mentally retarded and their families across the country. It has presented the principles that underlie these approaches and has described innovative service models based on these. These new principles and practices may herald a fundamental difference in the way in which service systems for the mentally retarded come to be structured in this country - systems based on services and not facilities, that enable individuals to remain in the community, in homes and families of their choice.

These principles and practices do not characterize the situation of the majority, or even a sizeable minority, of mentally retarded individuals in the country. Whether they will come to in the future, and if so, when that will occur, remains an unanswered question at present. This clearly depends upon a multitude of factors - e.g. commitment at county, state and federal levels; provision of incentives to encourage change in current programming; funding targeted for this purpose.

It must be realized that the innovative approaches reported are the latest steps in an evolution that has been occurring for some time:

> For almost a quarter of a century, services to people with disabilities - and particularly services to people with developmental disabilities - have been in a state of flux. Central to this process has been the transformation of the system of services from institutions to communities. With terms like deinstitutionalization, normalization, group home, least restrictive

environment, continuum of services, home-like environments, or community-based services characterizing the direction, change has been the status quo for the entire career of most workers in the field.[19]

As this report evidences, the field appears to be presently evolving further in this direction, experiencing a distinct shift in the paradigms that guide service development and delivery at the cutting edge. Whether, how quickly, and how successfully these new paradigms will come to characterize support and residential services to the majority of mentally retarded individuals across the country remain to be seen.

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[19] Knoll, James A. et al, Family Support Services in the United States: An End of Decade Status Report, Cambridge, MA.: Human Services Research Institute, 1990.

STATE MATERIAL RECEIVED

Materials on family support services and/or innovative residential programs for the mentally retarded were received from the following states:

Arkansas

Colorado

Connecticut

Illinois

Maine

Massachusetts

Missouri

New Hampshire

New York

North Carolina

Oklahoma

Oregon

Pennsylvania

Tennessee

Texas

Wisconsin

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